

Genetics Task Force Subcommittee Two Report

Subcommittee Title: State Mandated DNA Collection/Genetic Testing

Subcommittee Chair: Maxine Hayes

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Part I Newborn Screening

I. Background

1. State law (Chapter 70.83 RCW) requires:
“... screening tests of all newborn infants before they are discharged from the hospital for the detection of phenylketonuria and other heritable or metabolic disorders leading to mental retardation or physical defects as defined by the state board of health: Provided That no such tests shall be given to any newborn infant whose parents or guardian object thereto on the grounds that such tests conflict with their religious tenets and practices.”
2. Board of Health regulations (Chapter 246-650 WAC) adopted pursuant to the statute direct hospitals to obtain blood specimens from infants and send them to the State Public Health Laboratory for testing. The specimens consist of a few drops of blood that are absorbed onto a filter paper form. The blood is allowed to dry before shipping.

II. The incidence of discriminatory actions based upon genetic information

A. Findings

1. Over one and one half million infants have been tested by Washington’s program since it was centralized in 1977. In the United States, nearly four million infants are screened each year in similar programs.
2. No incidents of discrimination related to the dried blood spot specimens are known to program staff. However, there is no active system of surveillance, and this observation does not rule out the possibility that there may have been misuses of the collected data.

B. Conclusions

1. There is no evidence of discrimination under the newborn screening program in Washington State.

C. Recommendations

1. None.

III. Strategies to safeguard civil rights and privacy related to genetic information

A. Findings

1. These specimens and the testing results are considered “health care information” under the State Uniform Health Care Information Act, Chapter 70.02 RCW; and as “personal records” under Release of Records for Research, Chapter 42-48 RCW.

B. Conclusions

1. The subcommittee felt that the protections in place for the newborn screening system appear to be adequate to protect civil rights and privacy.

C. Recommendations

1. None

IV. Remedies to compensate individuals for inappropriate use of genetic information

A. Findings

1. The Uniform Health Care Information Act provides that action can be brought against a “...health care provider or facility who has not complied with this chapter.” Relief is limited to actual damages and attorney fees and other expenses of bringing the action. Relief must be sought within two years after the cause of action is discovered.
2. The Use of Records for Research statute provides that any unauthorized disclosure by a researcher of individually identifiable personal information obtained from a state agency is a gross misdemeanor and that any violation of the statute may subject the researcher or state agency to a civil penalty of not more than ten thousand dollars for each violation.

B. Conclusions

1. Both the Uniform Health Care Information Act and Use of Records for Research statute provide remedies for inappropriate use.

C. Recommendations

1. None.

V. Incentives for further research and development on the use of DNA to promote public health, safety and welfare

A. Findings

1. Newborn Screening program policy allows use of the specimens for research with appropriate safeguards.

B. Conclusions

1. The subcommittee judged that protections provided by Department of Health policy, DSHS/DOH Human Subject Research Review Board policy, and Chapter 42.48 RCW, Release of Records for Research appear to be adequate to protect individuals without unnecessarily impeding research to promote public health safety and welfare.

C. Recommendations

1. None

Part II Mandatory DNA Collection for Forensic Purposes

I. Background

1. Recently amended state law, DNA Data Base, Chapter 43.43 RCW, requires that:
“Every adult or juvenile individual convicted of a felony, stalking ... harassment ... or communicating with a minor for immoral purposes ... must have a biological sample collected for purposes of DNA identification analysis ...”
2. The samples are to be tested and may be retained by the Forensic Services Bureau of the Washington State Patrol.
3. The statute restricts uses to “... identification analysis and prosecution of a criminal offense or for the identification of human remains or missing persons” or “... improving the operation of the *[DNA identification]* system.”
4. The statute allows the Patrol to submit DNA test results to the Federal Bureau of Investigation (FBI) combined DNA index system (CODIS) which is authorized under the DNA Identification Act of 1994(42 U.S.C.A§14132).

II. The incidence of discriminatory actions based upon genetic information

A. Findings

1. No information was found related to possible discriminatory actions. However, there is no active system of surveillance, and this observation does not rule out the possibility that there may have been misuses of the collected data.
2. The sections of DNA that are analyzed have been carefully selected to avoid regions related to any medical condition or disease.

B. Conclusions

1. No incidents of discriminatory actions were identified.

C. Recommendations

1. None

III. Strategies to safeguard civil rights and privacy related to genetic information

A. Findings

1. Uses are specifically restricted in both state and federal law
2. The tests do not reveal information relating to medical conditions or disease.

B. Conclusions

1. The majority of the Subcommittee concluded that protections appear to be adequate.
2. A minority advocated for destroying the specimens after they are tested and the DNA code has been entered in the database. A Minority Opinion will be submitted with the final report.

C. Recommendations

1. None

IV. Remedies to compensate individuals for inappropriate use of genetic information

A. Findings

1. The state law does not provide specific remedies beyond the existing tort system.
2. The federal DNA Identification Act of 1994 establishes criminal penalties for individuals who knowingly violate privacy protection standards and provides that access to the system is subject to cancellation if privacy requirements are not met. There are no specific remedies for individuals for inappropriate use.

B. Conclusions

1. Federal law provides penalties for inappropriate use, neither federal nor state law provide specific remedies to individuals, beyond the existing tort system.

C. Recommendations

1. None

VI. Incentives for further research and development on the use of DNA to promote public health, safety and welfare

A. Findings

1. State law does not allow use of the samples or test results for research beyond that which may "... improve the operation of the system..."
2. The federal law allows use of the test information if personally identifiable information is removed, for "... a population statistics database, for identification research and protocol development purposes, or for quality control purposes."

B. Conclusions

1. The subcommittee observed that, given the limited nature of the data provided by testing, further incentives are not warranted.

C. Recommendations

1. None

Part III Summary

The subcommittee found that safeguards for these two specific mandated systems appear to be adequate to protect civil liberties and privacy. However, it could identify no circumstances that would justify the creation of any additional mandatory DNA/genetic testing systems. Members caution that any infringement on an individual's rights to free choice regarding their DNA/genetic information is perilous and to be avoided in all but the most specific and compelling circumstances found in these two systems.

Finally, the subcommittee recommends that the Task Force at large consider *A Proposed Model Law to Prevent Genetic Discrimination* which was developed by the Council for Responsible Genetics, a non-profit/non-governmental organization devoted to fostering public debate about the social, ethical, and environmental implications of the new genetic technologies. This model law was developed specifically to help address issues that the Task Force has been charged to review. See the attached document for the text of this law.